

# Story and science

## How providers and parents can utilize storytelling to combat anti-vaccine misinformation

Ashley Shelby\* and Karen Ernst

Moms Who Vax; Twin Cities, MN USA

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With little or no evidence-based information to back up claims of vaccine danger, anti-vaccine activists have relied on the power of storytelling to infect an entire generation of parents with fear of and doubt about vaccines. These parent accounts of perceived vaccine injury, coupled with Andrew Wakefield's fraudulent research study linking the MMR vaccine to autism, created a substantial amount of vaccine hesitancy in new parents, which manifests in both vaccine refusal and the adoption of delayed vaccine schedules. The tools used by the medical and public health communities to counteract the anti-vaccine movement include statistics, research, and other evidence-based information, often delivered verbally or in the form of the CDC's Vaccine Information Statements. This approach may not be effective enough on its own to convince vaccine-hesitant parents that vaccines are safe, effective, and crucial to their children's health. Utilizing some of the storytelling strategies used by the anti-vaccine movement, in addition to evidence-based vaccine information, could potentially offer providers, public health officials, and pro-vaccine parents an opportunity to mount a much stronger defense against anti-vaccine messaging.

### The Power of Experience: Anecdotes Become Evidence

The image has gone viral: a photograph of a newborn, his body severely bloated and his skin covered in rashes from head to toe. He is intubated—in his mouth, down his nose, in his scalp, and in his chest. The caption, written by the newborn's parents, tells us that the child's state was caused by a vaccine.

"Ian Gromowski was born healthy until received his hepatitis B shot on his eighth day of life. Hours later, he was crying inconsolably, refusing to eat, and taking on seizure-like postures. His platelet count plummeted."<sup>1</sup>

By day 47, Ian is dead.

The photo, the story—which took place in 2007—and the originating blog<sup>2</sup> were, and continue to be, passed from person to person, and from online forum to forum. Ian's parents appear to want their son's story shared widely, reporting on their blog, "We

have seen an explosion in vaccine administration (sic), from 12 in our generation to 38 given today. While we stress that Scott and I are not against vaccines, we are certain every parent should know the risks and benefits of each, and only then make decisions. Educate yourself. Your child's life depends on it!"<sup>3</sup>

As Ian's story spread, parents began to respond online, especially through social media, such as online forums, comment sections, Facebook, and Twitter. One mother on a CafeMom forum post titled "Baby Ian's brave struggle with the Hepatitis B vaccine" responds to the story by saying it "reminds me of how important it really is to stay educated about vaccines and many other things that are not safe for our kids despite what doc's [sic] or any other government website will tell us...."<sup>4</sup>

However, for someone with a background in science or medicine, the Gromowskis' blog paints a more nuanced portrait of Ian's short life. In it we learn his mother was induced due to preeclampsia. Ian aspirated meconium. He also had allergies to various antibiotics. Further, doctors believed Ian had contracted a virus. In fact, Ian did not receive the hepatitis B vaccine until he was eight days old, because he had been in the NICU since birth.<sup>2</sup> Finally, when Ian seemed to be improving, he was accidentally administered the very antibiotic he was allergic to before his condition had rapidly declined.<sup>2</sup>

"My father-in-law Larry said all along the cause was the hepatitis B shot. Scott and I knew the same and kept telling the doctors at St. Joe's this. No one listened. Later, when we were at Children's Hospital, nearly a dozen specialists saw Ian. All said about the same thing, "Something insulted his system, but it was not due to my specialty." [sic]. No one could figure out what was doing the insulting. Again and again we suggested the vaccination as the cause. We were told each time it was impossible. He was poked, prodded and tested for the rarest of rare diseases, yet the vaccination explanation would not be considered. We could not figure out why not. While Scott and I insisted it was the hepatitis B vaccine, we were continually told that this was not possible."<sup>2</sup> The Gromowskis' pain and grief led them to look for answers, and when none were provided they were certain the vaccine was the only possibility left.

This powerful narrative—with its themes of dismissive doctors, its devastating outcome of an ostensibly healthy baby quickly becoming critically ill, and its impossible-to-forget accompanying photos—presents a challenge to health care professionals,

\*Correspondence to: Ashley Shelby; Email: [ashelby@voicesforvaccines.org](mailto:ashelby@voicesforvaccines.org)  
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public health workers, and parents who vaccinate their children and are concerned about the rise in vaccine-preventable disease due in part to lower immunization rates.

Without access to Ian Gromowski's medical records, the account of Ian's parents is the sole primary source on which to judge this medical event. As a result, any commentary about what caused Ian's death would be guesswork. Responding to a narrative like Ian's with a guess is as unsatisfactory as the inability to pinpoint the cause of his illness was to his parents in the first place. In the absence of absolute answers, parents often make up their own minds. The Gromowskis believe the hepatitis B vaccine killed their baby, and they have made it their mission to warn as many new parents about the vaccine as possible. This dying infant, they seem to suggest, could be your child.

In the blog, Deanne Gromowski tells parents: "You be the judge, after you read the facts and see the pictures."<sup>2</sup> Thousands of parents have done just that—and agree with the Gromowskis that the hepatitis B vaccine killed their newborn. Those who question the verdict, and there are few, are sometimes publicly shamed. When one mother responded in an online forum that "many metabolic mitochondrial disorders (many without names yet) present just like this around the one week mark and lead to death within a few weeks to months," another mother responded with: "wow....just..wow...how ignorant of this mother to suggest such a thing."<sup>4</sup> Responding to Ian's story can seem problematic to parents who might doubt the vaccine connection to the newborn's death, because such doubt could appear callous and unsympathetic. The Gromowskis, after all, have laid out their grief in order to prevent other babies from suffering the same fate as Ian. It's clear their intentions are good, no matter their position on vaccination.

And so, perhaps unsurprisingly, this story of "vaccine injury" has gone mainly unchallenged and unexplained virtually anywhere it has been posted, and has become a permanent part of the anti-vaccine machinery of fear and doubt. It has also become emblematic of the anti-vaccine movement's approach to the conversation about vaccines. Ian Gromowski's story is so powerful, so pervasive, and so difficult to refute because it is just that: a story. And personal accounts, particularly as utilized by the anti-vaccine movement, are seemingly immune to facts.

### Controlling the Conversation: Anti-Vaccine Messaging and Social Media

As a result, a substantial part of the vaccine discussion among parents takes place on anti-vaccine websites, such as Age of Autism,<sup>5</sup> Say No to Vaccines,<sup>6</sup> Naturalnews.com, and countless other sites. Facebook offers a variety of anti-vaccine pages. For example, "My Child's Vaccine Reaction" Facebook page, filled with firsthand accounts from parents of what they believe to be their children's physical reactions to vaccines, has 4,952 "likes"—and counting.<sup>7</sup> "Dr Tenpenny on Vaccines" has 38,901.<sup>8</sup> Vaccination Information Network (VINE), run by Erwin Alber, who has suggested vaccines cause homosexuality,<sup>9</sup> has 30,116 likes.<sup>10</sup> The Vaccine Machine, another anti-vaccine site that, among other things, collects "vaccine injury" stories, has 12,600 likes.<sup>11</sup>

Each "like" is an endorsement of the content of these anti-vaccine pages by an individual, often a parent, who has read through them. Each individual "like" is then seen by—or promoted to—that person's network of Facebook friends. Interested friends click on the Facebook page link, and the cycle begins again, except now the page's reach is even greater. These online communities are gathering places for parents who choose not to vaccinate their children, and who share their stories in order to warn other parents of the "dangers" of vaccination. They are the modern-day equivalent to the talking stick, except that the reach of such stories is global, and their transmission instant.

The engine driving these online communities and thereby driving the anti-vaccine message deeper and deeper into the collective parenting psyche are stories like Ian's. With little or no science or evidence-based information to back up claims of vaccine danger, anti-vaccine activists have relied on the profound power of storytelling to infect an entire generation of parents with fear and doubt. And so some may argue that the success of the anti-vaccine movement is due to the fact that they have told a better story.

Perhaps the most pervasive narrative told by the anti-vaccine community is the "overnight autism" account. It goes like this: a parent takes her child to the pediatrician for his MMR vaccine. The next morning, or sometimes hours later, he is glassy-eyed, non-responsive, and has lost all language gained up to that point. There are countless examples of this terrifying story online,<sup>12,13</sup> including on the website Following Vaccinations, which collects stories about post-vaccine reaction from parents of autistic children.<sup>14</sup> In an age where a parent can Tweet from the exam room or post links to any article on Facebook,<sup>15</sup> these stories spread quickly, and with little counter-commentary from health care professionals<sup>a</sup> or other parents who choose to immunize their children, the accounts began to ossify into "vaccine information," appearing alongside the Centers for Disease Control (CDC) website in Google searches for "vaccines."

In fact, these stories—and the sites on which they appear—become veritable "echo chambers" because the site and page administrators so tightly control the content and comments appearing on them. For example, noted anti-vaccine activist Sherri Tenpenny writes on her Facebook page "pro-vaccine antagonism and antagonists are not welcome, and will be removed. I reserve the right to maintain conversations...within this community that are educational, informative, and helpful...from our point of view."<sup>16</sup> Thus, any voices speaking in support of vaccines are immediately deleted and barred from participating on these pages.<sup>b</sup>

These parent accounts of perceived vaccine injury, coupled with Andrew Wakefield's disastrous and fraudulent research study linking the MMR vaccine to autism,<sup>17</sup> created a substantial amount of vaccine hesitancy in new parents, which manifests in both vaccine refusal and the adoption of delayed vaccine schedules.<sup>18</sup> The 2009 National Immunization Survey of 11,206 parents of children age 24–35 mo revealed that 25.8% delayed their children's vaccines. 8.2% of them refused vaccines.<sup>19</sup>

The "overnight autism" narrative is a horrifying story, one designed to frighten parents out of vaccinating. It suggests a kind

of dark chaos at the end of a needle. And it clearly has worked. This anecdote, and others like it, resonated across the country. It was so effective in creating doubt among parents<sup>20,21</sup> that even staunch pro-vaccine parents sometimes confess to being anxious during their child's MMR vaccination, including one of the authors of this commentary. That it has no science or evidence to support it matters little in the world of social media.

The continuing influence of Wakefield is an example of this. Supporters of Dr Wakefield have created a "Dr Wakefield Justice Fund,"<sup>22</sup> which solicits donations to fund Wakefield's defamation lawsuit against the British Medical Journal and the journal's editor, Fiona Godlee. Several supportive Facebook pages also exist on Dr Wakefield's behalf, including "Dr Wakefield's work must continue," which has garnered more than eight thousand "likes."<sup>23</sup> These sites do not merely serve as platforms for a single doctor's efforts at reputation rehabilitation. Because of the nature of social media, the sites encourage story-swapping and link-sharing. Examples chosen at random from the Dr Wakefield's work must continue Facebook page include the following:

- A link to a story on a website geared toward mothers, titled: "Vaccine Court Awards Millions to Kids with Autism But Won't Admit the Truth".
- A post from a parent, reading: "We saw a complete regression in our little boy when he had the MMR, before this he was completely healthy. He had a fever and within a few weeks lost eye contact, had very severe diarrhoea and autism pursued. [sic] I am very interested in understanding fully the impact of the MMR on the body, I've heard of autoimmunity but I'm not really understanding what it fully is, I want to know why our children's bodies react to this live virus. I wondered if you could direct me anywhere with good info explaining this fully?" (The site's manager and members ask for the woman's email address so they can send her Wakefield's *Lancet* study<sup>24</sup>).
- A call for signees to a petition to President Barack Obama against "Mandatory vaccination." "It has only 2000 signatures and I am sure there are more people who would be interested in supporting it. Thank you very much! Karina"

These Facebook pages and online forums are places where beliefs are built, and, possibly, places that exacerbate misunderstandings about the science of vaccines—particularly risk-benefit analysis. In a 2012 paper published in *Science*, researchers found that online comments on science articles had a significant negative impact on science understanding. In the study, roughly two thousand people were asked to read a neutral news story about nanotechnology, which also contained a comment section consisting of invented comments. While all of the subjects read the same article, one group read a series of negative, even uncivil comments regarding the content of the article; the other group read comments more polite in tone. "Disturbingly," authors Dominique Brossard and Dietram A Scheufele wrote, "readers' interpretations of potential risks associated with the technology described in the news article differed significantly, depending only on the tone of the manipulated reader comments posted with the story." Put another way, just the tone of reader comments can make a substantial impact on the way the audience thinks about the technology described.<sup>25</sup>

It is therefore troubling when parents turn to sites like the aforementioned Facebook pages or anti-vaccine blogs for vaccine information, even when they begin to doubt the veracity of anti-vaccine claims. Take this exchange on the Facebook page "The Vaccine Machine," for example. An anonymous poster asks: "Is there evidence of vaccine injured children being injured due to the vaccine? I posted an article on what is found in vaccines and got attacked by a bunch of scientists telling me a bunch of rubbish on how vaccines r [sic] safe and no parent can prove vaccine injured children is due to vaccine! [sic] They want scientific evidence that vaccines r [sic] bad!"

Among the 65 responses this poster received<sup>11</sup> were:

- "Sometimes vaccines are more useless than bad: for example the flu shot and sometimes they are more ineffective than "bad" like with pertussis vaccine. There are lots of reasons to say no to vaccines and none of them require you to explain [sic] your reasons to a bunch of egghead scientist types."
- "Quit arguing with those people, they have never done any research."
- "Doctor vaccinates his own child at 3 years. Loses over half of his vocabulary. Brings child home to momma, she asks him what happened to my baby the light in his eyes is gone. You are going to find a way to fix him she says, father and mother are now anti vaccine. True story, friends of the family."

Even a woman identifying herself as a nurse comments that "the ingredients lists [sic] are full of known neurobiological toxins and carcinogens like formaldehyde, mercury, aluminum, etc. Sorry... but you'd have to be an idiot to believe these substances are safe for any... much less for all!"

This is an emotion-driven exchange. The words are meant as warnings, and appeal to emotion rather than reason. In addition, the messages are conveyed through storytelling, with narratives ranging from "vaccine reactions" affecting the writer or someone he or she knew to accounts of a "friend" going from certainty about the safety of vaccines to doubt. Finally, some in this exchange invoke their authority to bolster a position: "I'm a nurse," for example. Such a comment is meant to suggest that there is significant disagreement about the safety of vaccination in the medical and healthcare communities in which they work, which is meant to create fear and doubt among parents.

Because of the nature of social media, the validity of these stories and the credibility of the individuals sharing them typically go unchallenged, as in the aforementioned thread. This is because they confirm the biases of those participating in that forum. An outsider stumbling upon the discussion could, in the absence of citation, documentation, or even a request for such, assume greater credibility for the claims than exists.

With the advent of social media networks such as Facebook and Twitter, and the rise of so-called "Mommy Blogs,"<sup>26</sup> such communication has been made vastly easier. And this ease of communication has served to change, for some parents, the tone of the conversation about vaccines. Not only are parents turning to the Internet for vaccine information, some are also engaging in the vaccine discussion in a way that resembles participation in social causes. For example, many anti-vaccine activists refer to their messaging as a "movement."<sup>27</sup> USC's Annenberg

School's Center for the Digital Future found that "almost two-thirds of online community members who participate in social causes through the Internet (64%) say they are involved in causes that were new to them when they began participating on the Internet."<sup>28</sup> It was natural that vaccines would enter the discussion in this way. The Internet creates communities for parents worried about vaccines, and once they have bought into the anti-vaccine rhetoric, participation in these online communities may feel like a cause to them.

### Story and Science: An Effective Combination

The tools used by the medical and public health communities to counteract the anti-vaccine movement include statistics, research, and other evidence-based information, often delivered verbally or in the form of the CDC's Vaccine Information Statements that are handed to parents prior to vaccinations. It's important to note that most of the CDC Vaccine Information Statements parents receive before vaccination dedicate nearly half of their information to detailing risks of the vaccine and providing information to parents on how to report severe vaccine reactions to the National Vaccine Injury Compensation Program.

This approach may not be effective enough on its own to convince vaccine-hesitant parents that vaccines are safe, effective, and crucial to their children's health. Utilizing some of the strategies used by the anti-vaccine movement, in addition to the use of evidence-based vaccine information, could potentially offer providers, public health officials, and pro-vaccine parents an opportunity to mount a much stronger defense against anti-vaccine messaging, which relies almost exclusively on personal narrative.

What if the mainstream narrative about a parent's experience of vaccines were different from the standard anti-vaccine trope of harm and toxicity? What if it was not one of "vaccine injury" or "toxicity" but was instead an account of a positive vaccine experience or, on the other end of the spectrum, one of vaccine-preventable disease? Consider this account from a mother whose five-week-old daughter contracted pertussis, which appeared on our blog, *Moms Who Vax*, in 2012. "She was hospitalized right away, and as her coughing spells became more intense and worrisome she was moved into the intensive care unit. There was very little that the doctors could do for her as she weathered through the peak phase of the illness. Pertussis causes intense coughing spells along with other respiratory complications, and is particularly dangerous for infants because of their immature respiratory system. Our baby had trouble clearing away the thick mucus in her airway and was continuously deprived of oxygen. The illness also placed considerable stress on her small heart due to the pressure that had built in her chest. Unfortunately, these consequences are typical for an infant with pertussis. The weeks that we spent in the hospital were very difficult. Our baby fought hard against a respiratory illness that her body was not ready to handle. Each day we watched her struggle for breath, unable to eat or sleep, and have to linger in pain. We are thankful for her strong will and for the good medical care that she received. After three weeks in the ICU her symptoms began to wane indicating that she was past the

peak phase of the illness."<sup>29</sup> Making this first-person account even more compelling is the accompanying photograph of the infant, alert, adorable, but intubated and clearly quite ill. The blog post, titled "Everlee's Story," was shared widely across social media, and as a result, the local CBS affiliate interviewed the mother and made her story their lead news item on the night it aired. Unlike statistics, Everlee's story was difficult to refute, and so we found little response to Everlee's story from the anti-vaccine community, both on our blog and across the social media landscape.

There's another pro-vaccine narrative nearly all parents who immunize their children can share, one that is, in the words of a pro-vaccine mom who has written for our blog, "the greatest story never told: the story of an uneventful vaccination. "When my son was two days old," she wrote on *Moms Who Vax*, "he received his first hepatitis B shot. Nothing happened. When my son was one month old, he received a second hepatitis B shot. Nothing happened. When he was two months old, he received the rotavirus vaccines, the pneumococcal vaccine, and Pentacel, a shot that protects against diphtheria, tetanus, pertussis, haemophilus influenzae b, and polio. Nothing happened, and nothing happened at four months when he received another dose of each." She goes on to recount the other well-child visits with their attendant immunizations, where "nothing happened."

She ends by addressing her fellow parents this way: "Earlier I said 'nothing happened,' but that just isn't true. Behind the scenes, my son's body was mounting antibodies to the antigens in the vaccines, a response that, should he ever be exposed to the actual disease, will help protect him."

Finally, one of the most powerful pro-vaccine narratives is the "anti-vax to pro-vax" conversion. Although rare, these transformations can touch vaccine-hesitant parents deeply. Sometimes these conversions take place because a parent's decision not to vaccinate has resulted in vaccine-preventable disease. For example, in 2012, a father from New Zealand named Ian Williams shared with a local newspaper his story of going from anti-vaccine to pro-vaccine after his son contracted tetanus and nearly died. He and his wife had chosen not to vaccinate their children because they felt vaccines were dangerous. Then his seven-year-old son, Alijah, contracted tetanus and fell critically ill.

"Blood is dripping from his mouth and he is saying 'save me daddy'...I was holding the hand of my kid who had an arched back, the muscles could break his bones at any second, and his heart could stop."<sup>30</sup> Alijah was put into an induced coma, and, eventually on life support.

Williams and his wife had done research online and felt that the risk of getting these diseases were lower than the risk of a severe vaccine reaction—a common belief among parents who do not vaccinate their children. Doctors told Ian that Alijah had a one in ten chance of dying from tetanus. Williams also told the paper that he and his wife "fell for the myths and conspiracies that pepper the Internet." Alijah was in the hospital for 26 d, and, his father says, faces a yearlong recovery process, where he will have to relearn how to eat and walk.

"It's been the worst nightmare ever, just horrible for everyone," Linda Williams told the paper. "If we can save just one



child going through this, then my task is done.” Their story went global quickly, shared across Twitter, Facebook, and beyond.

Technically, Ian and Linda Williams’ story is an anecdote, a personal experience. The anecdote is anathema to medical professionals, and for good reason. Anecdotes are not evidence-based data. They cannot be replicated. Because of this view of anecdote and storytelling within the medical community, as well as being relative latecomers to the social media game, the medical and public health community has been a step behind the anti-vaccine movement in the messaging about immunization.<sup>4</sup> There is already some evidence to suggest that one of the most persuasive and effective means of communicating vaccine information to some parents is the anecdote.<sup>31</sup> A story shared between parents, or between parent and provider, can sometimes have more impact than a Vaccine Information Statement handed to a parent at a well-child visit.

It may be worthwhile for providers to consider utilizing anecdote and storytelling, along with reliable, fact-based vaccine information, to reach parents in the exam room and beyond. Parents who immunize their children and feel strongly about the decision—a group that terms itself “pro-vax”—have a responsibility to tell their own stories and advocate for timely immunization. Providers and parents can work together to make a positive impact on immunization rates.

It’s important to remember that health care providers are often parents themselves, individuals who have had to make the same vaccine decisions their patients are making. It may be worth these providers’ time to ask themselves why they chose to vaccinate their children. A worried parent may be reassured by knowing that his or her child’s doctor chose to vaccinate his or her own children, and why.

Another opportunity in the exam room to utilize storytelling is to talk about cases of vaccine-preventable disease. Doctors and public health professionals have often seen these kinds of cases, sometimes even resulting in death, over the course of their medical careers. Sharing one of these stories with a vaccine-hesitant parent, in a non-threatening and non-judgmental manner, can be an effective way to utilize storytelling in the vaccine conversation.<sup>4</sup>

Some providers have successfully used this provider-as-parent approach in their own practices, including Wendy Sue Swanson, MD, MBE, who refers to herself as “Seattle Mama Doc,”<sup>32</sup> and Lara Zibners, MD.<sup>33</sup> Both providers have a blog and a Twitter account, and both utilize a conversational tone that blends scientific data and personal experience: storytelling with science. They speak to parents as a parent who just happens to be a pediatrician, reminding vaccine-hesitant parents that even though they are doctors, they have the same concerns as any other parent. Considering the issue from this perspective, vaccine-hesitant parents may come to realize the irrationality of the idea that a pediatrician-parent would inject their own children with harmful “toxins” if there were any validity to the claims of the anti-vaccine movement.

Further, physicians may not realize that they have potential partners in the waiting room—any parent who chooses to vaccinate is potentially a pro-vaccine parent. There is a growing passion

among parents who vaccinate to begin speaking up about the importance of immunization, and yet we continue to hear from these parents that they don’t know how to help. Physicians and other providers may consider utilizing these parents as “vaccine ambassadors” by putting a call out among their patients: a flyer in the waiting room, a notice on the website. “Vaccine ambassadors” can volunteer to provide their e-mail addresses or phone numbers to the clinic to hand to vaccine-hesitant parents. Rather than dispensing any medical advice (the guidelines regarding this would be discussed between ambassador and provider ahead of time), these ambassadors would simply share the reasons why they vaccinate their children. In this way, that powerful peer-to-peer communication can take place under the auspices of a health care setting; the parent ambassadors then partner with the clinic in an effort to reach the same goal.

Providers can also choose to direct their patients to trusted resources beyond the CDC website, including pro-vaccine blogs, parent-driven organizations like Voices for Vaccines, or any one of numerous pro-vaccine Facebook pages, while making it clear these sites are not connected with the particular clinic or health care system for which the provider works. It’s time for parents to begin working with medical providers and the public health authorities to reframe this discussion by harnessing the power of storytelling and to begin pushing back against anti-vaccine misinformation, particularly through partnerships with providers and through social media.

## Summary

Social media and blogs have blurred the lines between virtual interactions and real-life interactions. Personal stories become public on the Internet, and parents feel an immediate, intense interest in these stories, which can spur them into taking action. The anti-vaccine movement has long understood the power of Internet storytelling, and its members have created virtual communities in which stories become facts that drive beliefs and inform medical decisions.

Pro-vaccine providers, healthcare workers, and parents can and must utilize this same paradigm. Creating story-based blogs like Seattle Mama Doc, Moms Who Vax, and other pro-vaccine blogs has been a good start. Online pro-vaccine communities tend to have less restrictive guidelines, partially because anti-vaccine comments are seen by community members as an opportunity to correct misinformation. As these online communities grow in number, more parents will engage and feel motivated to take action—both in terms of their own decisions about immunization and about reaching out to other parents.

Providers can connect with both vaccine-hesitant and pro-vaccine parents through storytelling in the exam room. Parents want to hear that pediatricians and family doctors vaccinate their own children, and they want to hear about their experiences with vaccination. Providers should consider making available a list of trusted online resources to provide to parents—particularly vaccine-hesitant parents—during exams. Providers can also encourage parents who are already confident about their choice to vaccinate to speak up about their decision and become

a part of online communities that share positive stories about immunization.

As a final note, we offer a personal example of how parents can be tapped to become vocal partners in this conversation, and how fruitful that partnership can be. In 2011, author Ashley Shelby wrote an op-ed in the *Minneapolis Star-Tribune* titled “Opposed to Vaccination? Let’s Make That Sting,” which argued for concrete consequences for parents who choose not to vaccinate their children. After reading the op-ed, co-author Karen Ernst reached out to Shelby, as she had already been very active online in vaccine conversations and was well known in these communities as a pro-vaccine parent. Since then, we have founded the Moms Who Vax blog, a zero-profit site (no advertisers or funding) that features first-person stories from parents; spoken at the Minnesota Department of Health Immunization Conference; become members of the MIPAC Vaccine Hesitancy subgroup; worked on a volunteer basis with the Minnesota Department of Health in developing better state immunization rules, and helped resurrect and reimagine the pro-vaccine organization Voices for Vaccines, which relaunched as a parent-driven advocacy group in January 2013. We are also leading the effort to develop a Minnesota Childhood Immunization Coalition.

We mention this example because we are not vaccine experts, providers, scientists, or public health professionals. We are simply parents who care about immunization and the health of our communities, and feel passionate about combating anti-vaccine messages—and we know of many more parents like us who would like to help. It’s time for providers and others in the medical and public health community to realize they have partners waiting in the wings. With stories and science, this is a partnership that can make a real difference.

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## Endnotes

<sup>a</sup>By counter-commentary, we mean specific responses to the individual narrative.

<sup>b</sup>This censorship is in noted contrast to the administration of pro-vaccine pages, which, in general, leave anti-vaccine comments posted in order to allow pro-vaccine parents and individuals with scientific background to correct the misinformation.

<sup>c</sup>“Web 2.0 may influence vaccination decisions by delivering information that alters the perceived personal risk of vaccine-preventable diseases or vaccination side-effects. It appears useful for public health officials to put effort into increasing the effectiveness of existing communication by implementing interactive, customized communication. A key step to providing successful public health communication is to identify those who are particularly vulnerable to finding and using unreliable and misleading information.” Betsch, Cornelia, et al. “Opportunities and challenges of Web 2.0 for vaccination decisions” Vaccines. Vol. 30, Issue 25, 28 May 2012, 3727–3733.

<sup>d</sup>It’s worth noting that sometimes such approaches can backfire with anti-vaccine parents, who may characterize such narratives as “bullying.” An anti-vaccine website, The Healthy Home Economist, even offers parents tips on “How to Resist Pediatrician Pro-Vaccine Tactics”: <http://www.thehealthyhomeeconomist.com/how-to-resist-pediatrician-pro/>. We believe storytelling works best with the vaccine-hesitant, not the staunchly anti-vaccine.

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